# The VIPER project: how we did the qualitative research

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Education Not Segregation – The Alliance for Inclusive Education
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## Contents

# Acknowledgements

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The research described in this report was carried out by the following staff researchers: Catherine Shaw, Natasha Willmott, Chloe Gill, Joanna Lea, Anita Franklin. The 'Vipers', a group of disabled young researchers, worked alongside the adult researchers, they are: Abadur, Becky, Benjamin, Emma, Fran, Harry, Hugh, John, Jo, Jonathan, Marti, Sam, Toby, Thomas, William and Yewande.

Other members of the VIPER project team have also played a key part in informing the development of the research design and the interpretation of the findings, they are: Tara Flood, Pamela Shaw and Zara Todd.

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# 1. Introduction

This report presents the methodology for the qualitative research element of the VIPER project. For background information about the project and the complete findings, please see the full report: *The VIPER project: what we found*.

The overall aim of the VIPER project is to improve services used by disabled children and young people[1] in England. Within its three year lifespan the project set out to:

- Investigate how services involve disabled young people in different types of decisions – decisions about long-term planning ('strategic' decisions) as well as decisions about the way things happen from day to day ('operational' decisions).
- Explore the impacts and benefits of disabled young people's participation.
- Understand the barriers to effectively involving disabled young people in decision-making.
- Seek out good practice and understand, from the viewpoints of services and disabled young people, what seems to work in supporting participation.
- Develop materials and resources with disabled young people to support their participation in decision-making.

## 1.1 Some language used in this report

Here are some of the key words and phrases we use in this report and in the VIPER project, with explanations of what we mean by them.

Some people use the words **participation** and **involvement** as if they mean exactly the same thing, but they are subtly different. If young people are **involved** in something, it suggests that somebody (usually an adult) is inviting or allowing them to take part. But if young people are **participating** they are taking part in a more active and equal way in a decision-making process. We therefore prefer to use the word **participation.**

The VIPER research looks into disabled young people's participation in **decision-making about services**. These are decisions that could affect

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[1] To make the report easier to read, from now on we will use 'young people' to stand for 'children and young people'.

lots of people who use those services now and in the future. In this research we do not focus on disabled young people's participation in individual decisions about their own lives (although this is of course important too!).

Some of the kind of decisions we were looking at are described as **strategic.** This means they are about long-term planning, for example making decisions about what kinds of services are needed and how much money should be spent on them. Other decisions are described as **operational**. These decisions are about what happens in a service or organisation from day-to-day.

We talk about services or organisations being **inclusive** (or not). By this we mean that they include everybody - disabled young people being included alongside their non-disabled peers.

When we use the word **VIPER** (all in capital letters), we are referring to the project as a whole, but when we say **Vipers**, we are talking about the disabled young researchers who participated in the VIPER project.

Researchers employed by NCB Research Centre and The Children's Society are referred to as **staff researchers**. However, the **VIPER research team** includes both staff researchers and Vipers.

## 1.2 Overview of research tasks, activities and Vipers' involvement

In order to further explore how disabled young people can successfully and meaningfully participate in decision-making about services, organisations and policies, we carried out qualitative research in eight organisations and services.

In addition to the qualitative research, the research programme included a review of literature and an online survey (for further details please see this report. The qualitative research element of the project was where we had the most Viper involvement[2]. Working with the team of staff researchers, Vipers were involved in a variety of research tasks and activities, outlined below (figure 2.1).

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[2] The literature review and online survey elements of the research had less Vipers' involvement because they were carried out at the outset to inform the development of the project and before the Vipers had been recruited and trained. However, Vipers have been involved in other ways with both these areas of the research work, including creating a summary of findings (for the literature review) and using the findings from both research elements to inform the development of questions for the qualitative research.

## Figure 2.1: Involvement of Vipers qualitative research tasks and activities

| | |
|---|---|
| **Sampling and design** | • Contributed to design of the qualitative research selection criteria<br>• Involved in selection of qualitative research sites<br>• Led design of questions for interview and focus group topic guides<br>• Design of additional research tools on a case by case basis (e.g. designing an online survey for schools linked to one of the projects we visited)<br>• Involved in design of consent forms for the young people taking part in fieldwork<br>• Involved in design of conduct of research e.g. ethical arrangements |
| **Fieldwork** | • Undertaking interviews with a range of participants e.g. strategic managers, project workers, commissioners, and volunteers (5 interviews conducted)<br>• Undertaking focus groups with disabled young people (6 focus groups conducted) |
| **Analysis** | • Contributed to data coding (interview and focus group transcripts)<br>• Led analysis of online survey (research tool used in one qualitative site)<br>• Contributed to thematic analysis - comparing emerging themes across a number of interviews and focus groups and projects visited |
| **Reporting** | • Meeting to discuss findings (including review of main findings from literature review and consultation)<br>• Recording and writing a report on their responses to the projects findings and recommendations |

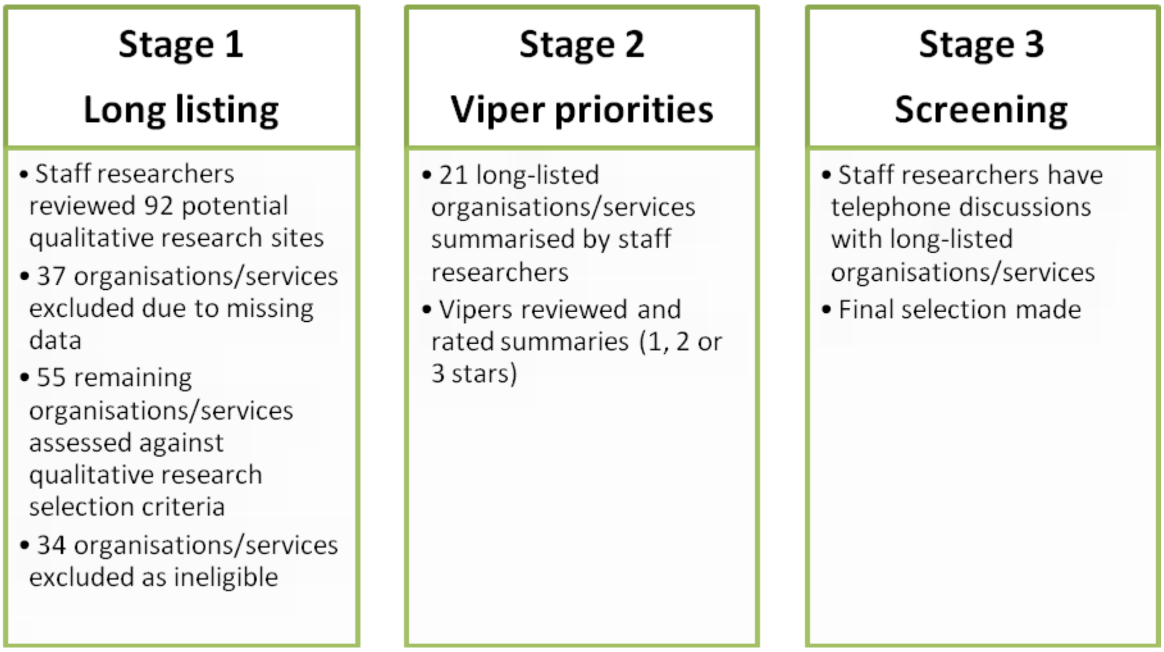
We will now outline in turn the main research tasks undertaken and the Vipers' involvement in each stage.

# 3. Sampling and design

We planned to carry out qualitative research in around ten organisations or services, identifying potential qualitative research sites from responses to our online survey.

Our selection process involved three stages, as outlined below.

**Figure 3.1: the selection process**



**Stage 1**

**Long listing**

- Staff researchers reviewed 92 potential qualitative research sites
- 37 organisations/services excluded due to missing data
- 55 remaining organisations/services assessed against qualitative research selection criteria
- 34 organisations/services excluded as ineligible

**Stage 2**

**Viper priorities**

- 21 long-listed organisations/services summarised by staff researchers
- Vipers reviewed and rated summaries (1, 2 or 3 stars)

**Stage 3**

**Screening**

- Staff researchers have telephone discussions with long-listed organisations/services
- Final selection made

Our sample frame for the qualitative research comprised the respondents from our online survey who had agreed to be contacted for further research[3]. We hoped to be able to cover as wide a variety of practices, issues, and types of organisation and service as possible. However, our choice was limited by a number of factors, including the need to select only from those who indicated that they were happy to take part in this aspect of the research, whether they were still involving disabled young people and their availability during the fieldwork period.

## 3.1 Stage 1: long listing

In all, 92 respondents to our survey (out of 204 currently engaged in participation work) stated that they would be interested in taking part in further research. We reviewed all 92 responses, using the survey data to identify those who seemed to be using innovative ways of involving

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[3] For further information on the online survey, please see 'What we found from the survey'.

disabled young people, and those where participation was reported to be making a tangible difference.

During this process, we initially rejected 37 survey responses due to insufficient information (e.g. key questions had not been answered, making it difficult to determine the nature of their participation work and who was involved). We then reviewed the remaining 55 survey responses again against our qualitative research selection criteria (Appendix A). Each of the 55 responses was reviewed and a short summary of their participation work and evidence against each of selection criteria was produced for each response.

Staff researchers and the Viper researcher's participation lead[4] then met and discussed each summary in turn. At this stage a further 34 survey responses were excluded as ineligible due to the following factors:

- the project/service was not currently undertaking any participation work
- the project/service had been undertaking participation work in the past, but this had ceased
- the project/service was involving disabled young people in individual level decision-making only (no involvement in operational and/or strategic decision-making).

## 3.2 Stage 2: Vipers' priorities

The first stage of the selection process yielded a refined long list of 21 organisations or services we could potentially visit. Staff researchers produced accessible summaries of the 21 organisations/services, outlining key information about each including:

- details about the participation work and the types of decisions disabled young people were involved in
- who was involved in the participation and their roles (e.g. ages and numbers of disabled children and young people and how they were involved)
- reported impact of their decision making.

The Vipers reviewed each summary and awarded star ratings, as follows:

- one star if the group had doubts as to whether the organisation/service matched our selection criteria
- two stars if they thought the organisation/service was a reasonable fit/might help us to explore our research questions
- three stars if the group thought the organisation/service would be definitely worth visiting.

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[4] The participation worker from the Alliance for Inclusive Education (ALLFIE). Their role was to support the participation of the Viper researchers in this project.

During the reviewing process, Vipers also noted down any gaps in the information the organisation/service had provided so far, so that in stage three the staff researchers could ask these additional questions to gain more understanding of the participation work.

The star ratings given by the Vipers to the 21 organisations/services are shown in table 3.1. Some organisations/services were awarded lower ratings due to incomplete information on some areas of their participation practice. In completing their ratings, Vipers made it clear that they were rating all 21 based on the information they had in the summary. It was agreed that, if during subsequent discussions with the organisations/services involved, we were able to obtain further information which addressed Viper concerns, these organisations could be selected for the qualitative research element.

These star ratings were used to help guide the final selection of organisations and services. Higher rated organisations and services were prioritised for selection alongside other factors influencing the final decision (e.g. variety of participation practice, types of organisation and availability of organisation/service during the fieldwork period).

**Table 3.1: Vipers' ratings**

| Star rating | No. of summaries which received this rating |
|---|---|
| 3 stars | 8 |
| 2.5 stars | 1 |
| 2 stars | 7 |
| 1.5 stars | 2 |
| 1 star | 2 |
| No star* | 1 |
| Total | 21 |

** One summary received no stars. The group of Vipers who reviewed it said that there was limited information provided by the consultation respondent as to how the disabled young people had been involved in the work and it therefore sounded 'boring' compared to other summaries they had reviewed.*

## 3.3 Stage 3: screening and final selection

During the star rating process, Vipers had highlighted some gaps in information provided by the organisations/services. In order fill in some of these gaps and to make a final selection, we phoned all shortlisted organisations and services and had detailed conversations about their recent, current and future participation activities.

The screening process was undertaken between August and October 2011 with all 21 possible research sites, however:

- We were unable to make contact with two of the organisations/services, despite several email and telephone calls to relevant individuals at each organisation.

- A further four organisations/services were unable to take part in the qualitative research, as their participation work with disabled young people had ceased (in three cases due to funding cuts and staff redundancies and in the fourth case due to participation work being scaled back).

- During the screening calls we were also able to determine that two of the 21 consultation responses related to the same project (the commissioner and the voluntary organisation delivering the project had both responded).

After screening calls, this left us with 14 possible organisations and services we could visit. In selecting our final sample, we took account of the following:

- Vipers' priorities (star ratings)
- the need for variety across the sample in terms of participation practices and approaches, types of organisation and ages of those involved
- geographical spread
- how established the projects/groups were (our research was interested in understanding the impact of disabled young people's participation and very new projects would not be able to demonstrate this)
- whether the organisations/services were available/functioning during the period when we needed to carry out fieldwork.

In the end we selected eight organisations and services to visit. As two of our projects were large, with more partners involved, it was decided that these would count as 'two visits' so that we had the resource to undertake the additional interviews required to fully explore their participation work.

During the fieldwork period, two of the eight organisations were unable to take part due to practical reasons. A replacement organisation was quickly identified for one of these organisations (which shared some similar characteristics in terms of the participation practices and ages of those involved with the organisation which had withdrawn from the qualitative research).

It was decided to replace one organisation with a health example, as no health service had been included in our final selection of the eight research sites (health services contacted in the screening stage either had ceased their participation work or did not respond to our emails and telephone calls). The Vipers had identified participation in decision-making by young disabled people in health services as something they thought was important, and therefore this was seen as a gap in our research sites.

As we had received very few consultation responses from health services, we adopted an alternative approach to recruiting a health site. Through their contacts, partners identified four health projects that were known to be actively involving disabled young people at the time of the research. Each of these four projects went through the same telephone screening process as the other potential fieldwork sites, and was assessed using the same criteria. The final choice of health project was based on its innovative structure, inclusive nature and reported successful impact on services.

Table 3.2 outlines the final eight organisations and services selected and their characteristics.

**Table 3.2: Organisations and services who took part in the qualitative research**

| Organisation /service | Sector | Age range of disabled young people involved | Groups of young people involved | Viper rating | Model of participation |
|---|---|---|---|---|---|
| A | Voluntary run – commissioned by local authority | 12-19 | Any additional access need; including learning and physical disability, sensory impairments and mental health needs | 2 | Youth parliament for disabled people |
| B | Statutory – local authority | 14-23 | Varied impairments /access needs | 1 | Championing /consultation group |
| C | Statutory – local authority | 11-25 | Any young person who considers themselves disabled | 1.5 | Young inspectors project |
| D | Voluntary run – commissioned by local authority | 12-19 | Learning disabilities or sensory impairments | 3 | Consultation group |
| E | Statutory – local authority | 15-22 | Visual impairments, learning disabilities and neurodiversity | 2.5 | Young people delivering participation training for practitioners |
| F | Voluntary run – commissioned by local authority | 13-24 | Learning and physical disabilities, sensory impairments, ADHD and neurodiversity. | 3 | Consultation group/strategic board - |
| G | Voluntary run – commissioned by local authority | 16-25 | Varied impairments /access needs | 3 | Consultation group |
| H | Self-advocacy voluntary organisation of disabled people | 8 – 25 (+ work with disabled adults) | Any disabled young person | N/A* | Self-advocacy network of disabled young people |

** There is no Vipers' rating for organisation H, as it was selected as a replacement after the rating exercise – see section 3.1.3 for more details.*

# 4. Research design

Although the overall research methodology and objectives were fixed and decided upon before Viper involvement (this had to be done in order to secure funding), Vipers were able to influence the research design within these predetermined parameters.

In the first instance, they devised the criteria for selecting the qualitative research sites. These criteria reflected their desire to investigate projects which had demonstrated real decision-making opportunities and which could demonstrate the impact of that participation. The group was not interested in sites that failed to show how they were influencing decision-making. When shown the descriptions of the various projects for selection, the Vipers provided the staff research team with strong follow-up questions based on their experience as young disabled people which were used in telephone discussions with each project.

The Vipers were heavily involved in the design of the research questions and tools used in the fieldwork stage. Vipers felt it was important to talk to a number of people in each site to gain different perspectives, and they identified strategic managers, project workers and young disabled people participating in the projects as key people to interview. They also identified others such as partners and commissioners as important to include.

Using these three main groups of people, Vipers devised questions around participation that they wanted to ask each group. Questions were based on the findings of the literature review, the VIPER project's definitions of what participation should look like and the selection criteria for the research sites.

Once questions were chosen, Vipers worked in small groups deciding which of the three groups, strategic managers, project managers and/or the young disabled people would be best placed to answer these. In many cases they decided that they wanted to ask all of these people the same questions for comparability.

The staff researchers then turned the questions into interview schedules (see Appendix B), which were adapted for each interview in consultation with the Viper young researcher working on that particular interview.

## 4.1 Fieldwork

We carried out site visits to each organisation or service, interviewing relevant project staff, young people, and decision-makers. Some interviews took place over the telephone. In one area we also carried out an online survey of schools that had worked with the participation project and in another we provided a short survey for project staff to administer with two young people who were unable to attend the focus group.

Of the 16 Vipers, a total of 13 Vipers expressed an interest in undertaking fieldwork. During the course of the fieldwork period (November 2011 to May 2012) six Vipers were directly involved in fieldwork interviews. A further seven Vipers had expressed an interest in doing fieldwork. However, they were unable to take up fieldwork opportunities when offered due to a number of reasons, including the location of fieldwork sites, dates for visits offered by research sites and Vipers' other commitments.

Fieldwork was conducted between November 2011 and May 2012. On each fieldwork activity (whether a site visit or telephone interview) a member of the staff research team was present[5] . At one research site the Viper participation lead attended face to face interviews to support the Vipers involved.

Vipers participated in fieldwork in all but two of the organisations visited, where it was impossible to organise due to the timing, location, and Vipers' availability during the school exam period.

When conducting interviews and focus groups, Vipers had a choice of roles, they could be:

- observer
- co-researcher (with a staff researcher present to support)
- lead researcher (with a staff researcher present)

None of the Vipers chose the observer role, and in all activities they were either co-researchers or lead researchers. They undertook interviews with project staff and local authority strategic managers and led focus groups of young people. The role of staff researchers was to support the Viper, keep time, and handle any tricky situations.

In all, six Viper researchers took part in the fieldwork across six of the eight fieldwork sites (between them undertaking six focus groups and five interviews. A further two Vipers were involved in designing and analysing an online survey for us in one of the research sites). Vipers undertaking fieldwork tasks and activities were paid, in the form of vouchers, £20 per day[6].

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[5] If the fieldwork involved running a focus group, a second researcher would often be present to lend a hand (by taking notes or helping with activities) whilst the Viper and other staff researcher would run the group.

[6] Vipers' time and effort was acknowledged in the form of gift vouchers. Vipers are paid £20 per each VIPER meeting they attend. Vipers are also paid for any additional work they undertake e.g. fieldwork and extra meetings when working in smaller task groups (e.g. analysis task group, literature review summary task group).

Table 3.3 outlines the number of interviews, focus groups, and surveys conducted during fieldwork. (See Appendix C for a more detailed breakdown of the types of people interviewed).

**Table 3.3: Number of fieldwork activities across all eight research sites**

| Fieldwork activity | Total number undertaken | Number conducted by Vipers |
|---|---|---|
| Interviews (with strategic managers, project workers, project partners and commissioners) | 28 | 5 |
| Focus groups with disabled young people | 8 | 6 |
| Short surveys | 2<br>(one with disabled young people who were members a project and one with schools involved with a participation project) | 1 (design) |
| Total | 38 | 12 |

Interview length ranged from approximately 45 minutes to 1.5 hours and focus groups with young people ranged from 40 minutes to 1.5 hours. The length of both interviews and focus groups were determined by both the access needs of the Viper involved and in the case of focus groups, the needs, and wishes of the young people involved. When planning visits to research sites the staff researchers liaised with the project workers and shared focus group plans with them to ensure that the content and timing of each focus group were accessible for the young people involved.

With the exception of one focus group[7], all interviews and focus groups were digitally recorded and transcribed for analysis.

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[7] All participants were asked for their permission for us to record interviews and focus groups for data accuracy purposes. One group of young people stated that they did not feel comfortable with the use of a recorder. Instead the two staff researchers present took it in turns to write notes on what was said in addition to posters and notes made by the disabled young people themselves during various focus group activities.

## 4.2 Making the fieldwork accessible

At the time of writing this report, there had been 12 Viper group meetings, where Vipers came together for a day to be trained in research skills and to advise on various aspects of the research[8]. Training sessions to date have covered:

- learning more about the VIPER project, its aims and research questions
- key concepts behind the research (for example exploring Viper understanding of participation, involvement, medical and social models of disability)
- research methods (including literature reviews, surveys and qualitative research)
- ethical issues in research
- question design (for qualitative research activities, including interviews, focus groups and small surveys)
- design of consent forms for young people involved in focus groups.

Methods used for each activity in training sessions were tailored to be accessible and engaging for all Vipers.

All activities were focused on learning through doing (rather than Vipers simply listening to staff telling them relevant information). Power point was banned by the group after two meetings as not being accessible.

Training sessions usually started with a game, which the staff would plan and would have some relationship to the skills we were aiming to develop at the meeting (for example, we devised a 'research ethics game', to support the Vipers to develop their knowledge of key research principles including confidentiality and anonymity).

We aimed to make the activities fun while developing skills. We found that activities where there was an element of moving or change in activity/ method after 15 to 20 minutes worked well in keeping the whole group engaged; role playing and small group work were particularly successful.

The training sessions were a two way process, as the project progressed increasingly Vipers themselves took responsibility for leading some sessions and prepared their own guides for conducting fieldwork (for example, Vipers produced 'how to' guidance on how to conduct interviews, focus groups, surveys and observations, which they could refer to later on when out on fieldwork).

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[8] At the time of writing, a further four meetings were planned to support the Vipers in the dissemination of the research findings.

Vipers also worked individually with staff researchers and the Viper participation lead to prepare for each fieldwork visit and telephone interview. Preparation involved telephone and face to face briefings prior to fieldwork, where the staff researcher and Viper could discuss which organisation/person they were planning to visit/interview, arrangements for the fieldwork (travel details and plan for the day) and to discuss any issues or concerns the Viper had. All Vipers were provided with briefing materials to prepare them for fieldwork in a format accessible to the individual Viper.

Fieldwork visits were also organised in a way that was most accessible for the Viper (and indeed for the services and young people we were visiting). In setting up fieldwork, staff researchers worked closely with the research sites to ensure that practical arrangements enabled Vipers to participant fully (e.g. interviews held at a convenient time, plenty of time built into the visit schedule to allow for breaks). Research sites were also helpful in advising us as to the best ways to tailor the research questions and activities used in focus groups to enable their young people to participate fully.

All fieldwork activities ended with a post fieldwork briefing, which gave both the staff researchers and Vipers involved an opportunity to reflect on the process and to discuss learning from the visit. Where more interviews were schedule for that site, there was also a discussion of what further questions should be asked and to whom.

## 4.3 Viper impact on the fieldwork

Overall, Vipers' participation in fieldwork has impacted on the research in a number of ways. Vipers were more direct in their probing of answers from managers, project workers and disabled young people, as they tried to understand the participation work and the views of all involved. If Vipers did not understand what an interviewee was saying, they would directly state this and request further details. For example, some Vipers, through the course of conducting an interview became aware of how different meanings were attached to the term 'participation' with sometimes participation used to mean simply taking part in an activity. Where inconsistencies occurred in accounts, Vipers were quick to ask for clarification.

The Vipers were also very observant during fieldwork visits, and were able to pick up on interactions and language that staff researchers did not always pick up on. For example, when some staff were being patronising and/or disempowering the young people, Vipers picked up on language used, tone and how these interactions affected group dynamics.

We were also aware through discussions at some research sites that the VIPER model of working (Viper and staff researchers working together on an equal basis) was of interest to others. It also provided the research with greater credibility, in that the VIPER project is itself a participation research project.

# 5 Analysis and reporting

## 5.1 Analysis

Transcriptions of all interviews and focus groups, along with researcher notes were uploaded to NVivo 9[9], an analysis software package, for the main analysis.

Prior to analysis, the staff researchers read through a sample of transcripts (including interviews and focus groups done by others) to become more immersed in the data. Following on from this process, a thematic framework was created (see Appendix C) drawing on the research questions, qualitative research selection criteria and overarching themes and sub-themes emerging from the data.

The development of the thematic framework was a collaborative effort between the staff researchers and the Vipers. The initial thematic framework was set up in NVivo 9 prior to start of the main analysis process so that staff researchers could assess the effectiveness of the framework in coding and capturing the main features of each organisations/services participation work. At the same time, the thematic framework was discussed at a Viper meeting. Vipers were able to view and discuss the overall thematic framework and tested its effectiveness by coding some transcript extracts for the themes of 'barriers' and 'impacts' (and their related sub-themes).

The purpose of this testing process was to ensure that proposed themes and sub-themes could be applied to the data with both staff and Vipers having a clear understanding of what to code where. Comments from both Vipers and staff researchers were reviewed and the thematic framework was developed further (with some alternative, collapsed, and additional themes created to better incorporate the data).

Once a thematic framework had been agreed, staff researchers started to code data for each of the organisations/services visited. Coding involved going through all sections of the data and asking 'what is this about' and applying one or more theme or sub-themes (a 'code' in NVivo) to that section of data. Once all data for a particular organisation/service was coded, the staff researchers were able to run queries in NVivo, a way of exploring the relationships between two or more themes within the analytical case (in this instance each organisation and service visited).

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[9] An analysis software package for qualitative and mixed methods research. For further details about NVivo 9, please visit http://www.qsrinternational.com/

Vipers were also involved in the coding process. A coding session was held at a VIPER group meeting, where groups of Vipers coded transcript extracts from a range of organisations and services visited and discussed their coding and interpretations with each other. In addition, two Vipers elected to undertake more coding, each working on three further interview extracts.

During the coding process, Vipers were involved in coding interviews and focus group data for six of the eight research sites (Vipers were unable to code data for two research sites due to delays, which meant fieldwork was still in progress at these two sites at the time of the VIPER meeting). Staff researchers then wrote up findings of each organisation/service visited, organising data under a series of key headings (addressing the research questions). A further analysis meeting was held, with a group of five Vipers who had expressed an interest in undertaking further analysis. During this meeting the Vipers undertook an across case comparison, comparing the practices, motivations and impacts reported across the research sites. One Viper elected to undertake analysis of a survey conducted with schools that were linked in with one of the research sites participation activities.

Having young disabled people involved in the data analysis of the qualitative research has given the analysis a different perspective and interpretation than it would have had without their involvement. The Vipers were able to pick up nuances in what was said that may have been overlooked or downgraded in importance without their involvement. For example, unpicking young people’s continued motivations for involvement in the activities; when they were not getting any feedback on their involvement or feeling that they were not making a difference.

## 5.2 Reporting and drawing up recommendations

Once the analysis process was completed, staff researchers collated the main findings and organised these under the following headings (relating to our research questions):

- who participates in decision-making?
- which disabled young people participate?
- where do disabled young people participate in decision-making?
- when do disabled young people participate in decision-making?
- how do disabled young people participate?
- why are disabled young people involved in decision-making?
- what difference does participation make?

A VIPER meeting was held, where Vipers reflected in detail on these findingsand discussed whether these were in line with their expectations. Vipers also drew on findings from the literature review and consultation and discussed what recommendations and changes they felt should happen as a result of what the research findings showed.

The research programme has now been completed, and Vipers will spend the final year of the project disseminating the findings and lobbying to increase the opportunities for disabled young people to take part in decisions across all the services they access.

# Appendix A Qualitative research site selection criteria

During the course of this project the project team and Vipers have reflected on what good participation 'looks like'. We decided that there are 10 important ingredients that make up high quality participation for disabled young people (table A.1). We used the ingredients of high quality participation to consider survey responses to assist in research site selection.

**Table A.1: The ingredients of high quality participation**

| **Ingredient** | **What this means** |
|---|---|
| 1. Participation of disabled young people is thoroughly **embedded** in the culture and practices of the organisation | • The organisation is committed to meaningful, inclusive, accessible and ongoing participation practice<br>• Participation is built in to the organisation's activities in a proactive and planned way<br>• A wide range of staff are involved - not just 'participation workers'<br>• There is an awareness of the value and importance of participation throughout the organisation<br>• Learning is shared across the organisation<br>• There are mechanisms for communication between management and young people<br>• Disabled young people have some control of all of the above |
| 2. There is a **wide range of opportunities** for disabled young people to participate within the organisation | • Participation takes place at operational, strategic and individual levels<br>• (In larger organisations) participation of disabled young people happens in a range of different services – and not just those specifically focused on disability<br>• Disabled young people have opportunities to participate in different types of decision e.g. planning, service delivery, evaluation, communications |
| 3. Participation opportunities are **inclusive** | • Disabled young people have equal access to participation activities, whatever their impairment<br>• All ages of 'young' people can participate<br>• Disabled young people can access 'mainstream' participation opportunities |

| | |
|---|---|
| 4. Participation activities are **accessible** | • Barriers are removed<br>• A range of different approaches and methods are used flexibly and creatively<br>• Activities are appropriate to the age, abilities and access requirements of the young people<br>• Disabled young people have a say about the methods and activities used |
| 5.Disabled young people **set the agenda** | • Disabled young people have choice over the decisions they participate in<br>• Young people take ownership and initiate work themselves |
| 6. Participation is a **positive and meaningful experience** for disabled young people[10] | • Disabled young people get something they value from their participation experience<br>• Disabled young people understand the purpose of the activities, and the ways in which their contributions will be used<br>• Young people feel that their contributions are valued by others<br>• Activities are also enjoyable in themselves |
| 7.Staff have appropriate **attitudes, understanding and skills** | • Staff understand the meaning of participation – they enable young people to speak out, they do not speak for them<br>• Staff give young people choice, they do not lead<br>• Staff treat disabled young people as individuals and support them to participate<br>• Staff work within the social model of disability<br>• Staff receive disability equality training |
| 8.Participation is **monitored and evaluated** | • Records are kept about participation activities and the young people who participate<br>• Feedback from disabled young people is collected and used to improve activities<br>• Evidence of impact is collected<br>• Evaluation findings are acted upon and communicated to young people and others<br>• Disabled young people participate in evaluation processes |

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[10] At the time of research site selection, this was not a separate ingredient. During the process of sampling and interview question development, Vipers agreed that this was an important ingredient which whilst implicit in other elements of our criteria, might not receive sufficient attention during the analysis phase. A decision was made to revise the criteria and define more fully what the Viper research team meant by positive and meaningful experiences.

| | |
|---|---|
| 9.Participation of disabled young people **brings about change** | • Disabled young people's participation is seen to make a difference - to individuals, services, organisations and beyond<br>• These changes are communicated back to the young people, and to others |
| 10. The organisation shows that it **values** disabled young people's participation | • Disabled young people are rewarded and recognised for their participation<br>• Participation is acknowledged at a senior level within the organisation, and this accurately reflects young people's own experience (i.e. not 'bigging up' a tokenistic experience in order to 'tick the box')<br>• Sufficient resources are allocated to enable ongoing meaningful participation |

# Appendix B Topic guides

## Strategic manager – topic guide template

At the start of the interview, we need to explain the following things to the strategic manager:

- What topics the interview will cover
- How long the interview will take (approximately 1 hour – check with interviewee they are okay to talk for between 1 to 1.5 hours)
- Ask permission to record the interview (or to take notes)
- Tell them about confidentiality and how it applies to this interview
- Tell them what happens next – we write a report in 2012 (we won't use people's/organisation's names in anything we write; we may use quotes, but we would make these anonymous). The report will be published and be available on the web. All participating case studies will receive a copy of the final report.
- Let them know there are no right or wrong answers – we want to hear their own views/experiences. They can refuse to answer any question
- Ask the person we are interviewing if they have any questions they would like to ask us before we start
- Check again that they give their consent to take part.

### Section A - Background:

Very briefly, we would like to find out more about you and your organisation.

1. What organisation/ project/ service do you work for?

2. What is your job title?

3. How are you linked to the participation work?
    - What is your role (what are your key responsibilities in relation to the participation work)?

    - How long have you been in this role?

### Section B - About the disabled young people involved in decision-making:

We would like to find out more about the disabled young people involved in decision-making.

RESEARCHER TO ADD IN DETAIL ABOUT EACH AREA OF PARTICIPATION WORK

4. Can you briefly describe the group or groups of young people who participate in decision-making about…
   a) your own organisation/ project/ service?
   b) other organisations/ projects/ services?

5. How are these disabled young people linked to your organisation/ project/ service?
   - Are they your own organisation/ project/ service users?
   - Are they a group that works with a range of organisations/ project/ services?
   - Are they linked to your organisation/ project/ service in some other way?

## Section C - About the participation work:

We are interested in finding out why your organisation/ project/ service involves disabled young people in decision-making in service planning and/ or delivery.

6. Where does responsibility for participation sit within your organisation/ project/ service?

7. Does your organisation/ project/ service have a policy or strategy relating to the participation of disabled young people?
   - How did the policy/strategy come about – what was it developed in response to?
   - What does your policy/ strategy cover?
   - Were disabled young people involved in its development?
   - What difference, if any, has it made to the organisation/ project/ service?

*For each area of participation work, ask the strategic manager…*

8. Why did you/ your organisation/ project/ service want to involve disabled young people in decisions about service planning and/ or delivery?
   - Why was the participation work set up?
   - Are non-disabled young people involved in the participation work?
   - **If yes**, why do you involve both non-disabled and disabled young people?

9. What are you hoping to achieve through your participation work?
   Prompts:
   - to steer the overall direction of organisation/ project/ service
   - to deal with operational issues e.g. how services are delivered
   - to make sure the service meets young people's needs and preferences
   - to empower disabled young people
   - to influence decisions makers
   - any other aims – if so, tell us more about these

10. How is the participation work funded?
    - Who funds the participation work?
    - How long is the participation work funded for?
    - How 'secure' is the participation work funding e.g. is it due to end soon?

11. Who else is involved in the participation work?
    Prompts
    - other staff
    - parents/carers
    - support workers
    - volunteers
    - senior offices
    - partner organisations
    - staff at a strategic level e.g. board of trustees

## Section D - How disabled children and/ or young people are involved in decision-making:

We are interested in finding out more about what kinds of decisions disabled young people are involved in making.

*For each area of participation work, ask the strategic manager…*

12. What kinds of decisions are disabled young people involved in making?

13. Who decided the areas that disabled young people can make decisions about?

14. Are the young people involved in decisions about <u>your own</u> organisation/ project/ service?

***If yes**, can you tell us more about what kind of decisions…*

- Are these decisions about strategic issues e.g. the development of new services or policies, how the organisation/ project / service is run?

- Are these decisions about operational issues e.g. what happens day to day?

- Are the young people involved in decisions about mainstream services (e.g. services for all young people) or specialist services (e.g. for certain groups of young people)?

- How does your organisation/ project / service include young disabled people in decisions (e.g. which methods do you use)?

15. Are the young people involved in decisions about <u>other</u> organisations/ projects/ services?

***If yes**, can you tell us more about what kind of decisions…*

- Are these decisions about strategic issues e.g. the development of new services or policies, how the organisation/ project / service is run?

- Are these decisions about operational issues e.g. what happens day to day?

- Are the young people involved in decisions about mainstream services (e.g. services for all young people) or specialist services (e.g. for certain groups of young people)?

16. What kind of changes was it hoped that disabled young people's participation in decision-making would bring about?

17. In reality, how much influence do disabled young people have over decisions?

## Section E - Impact of disabled young people's participation:

We would like to find out more about the impact of disabled young people's participation in decision-making.

18. What has changed or improved as a result of involving disabled young people in decision-making?
    - Can you give us some specific examples of things that have been changed/improved?
    - What did it look like before and after?
    - Why is this now improved?
    - How has this had an impact on the service, the wider organisation(s), the staff, the young people who use the service?

19. Have young disabled people been involved in finding out what has changed or improved as a result of their involvement in decision-making?

    Prompts:
    - have they helped design evaluations?
    - have they shared their views in evaluation?
    - have they been co-researchers (undertook data collection or analysis)?

20. Has the young people's participation in decision-making led to wider changes in the local area (e.g. other services, in strategies or in policies that affect disabled young people)?

21. Has the young people's participation in decision-making led or contributed to wider changes nationally (e.g. national campaigns or policies)?

22. Through involving disabled young people in decisions, what has changed for other disabled young people who use your own or others' services?

23. Do you share information about what has changed or improved as a result of disabled young people's participation?
    - Who do you share this information with?

24. What have you personally learnt as a result of being involved in the participation work?

## Section F - What has worked well and lessons learnt:

We are interested in finding out what has worked in terms of your involvement of disabled young people in decision-making. We want to find out more about what 'good practice' is and what supports it.

*For each area of participation work, ask the strategic manager…*

25. What has worked well in terms of involving disabled young people in decision-making?
    - Why do you think this has worked well?
    - Did your organisation/ project/ service achieve the changes/improvements you wanted to see?
    - Did the young people involve achieve the changes/improvements they wanted to make?

26. What have you learnt about involving disabled young people in decision making through your participation work?
    - What did your organisation/ project/ service need to do in order to make participation of disabled young people happen?

27. Have you had any difficulties in involving disabled young people in decision-making?
    - How did you overcome these difficulties?
    - Is there anything you would do differently if you had the opportunity?
    - Are there any areas that you are actively trying to improve or learn new practice?

## Plans for the future

Before we finish the interview, we would like to ask you about the future plans for your participation work.

28. What are the plans for the future of the participation work?

29. Who will decide what happens in the future?
    Prompts:
    - young people currently involved in participation work
    - other young people
    - project worker(s)
    - yourself
    - funder
    - other people – who

30. What would need to happen to further embed participation across your organisation/ project/ service?

***If applicable****, ask the strategic manager…*

31. What needs to happen in order to enable disabled young people to participate in decisions alongside their non-disabled peers?

32. What needs to happen in order to involve disabled young people with more complex needs (e.g. communication needs, autistic spectrum disorders etc.) in decision-making?

33. What advice would you give to similar organisations/ projects/ services about how to effectively involve disabled young people in decision-making?
    - Why should they involve disabled young people?
    - What benefits would it bring to them/their organisation/ project/ service?

34. Anything else you would like to say about the participation of disabled young people in decision-making?

**That's the end of the interview – thank you for talking to us!**

## Project worker – topic guide template

At the start of the interview, we need to explain the following things to the project worker:

- What topics the interview will cover
- How long the interview will take (approximately 1 hour – check with interviewee are they okay to talk for between 1 to 1.5 hours)
- Ask permission to record the interview (or to take notes)
- Tell them about confidentiality and how it applies to this interview
- Tell them what happens next – we write a report in 2012 (we won't use people's/organisation's names in anything we write; we may use quotes, but we would make these anonymous). The report will be published and be available on the web. All participating case studies will receive a copy of the final report.
- Let them know there are no right or wrong answers – we want to hear their own views/experiences. They can refuse to answer any question
- Ask the person we are interviewing if they have any questions they would like to ask us before we start
- Check again that they give their consent to take part.

## Section A - Background:

Very briefly, we would like to find out more about you and your organisation.

Note to academic researcher – just use one or two questions here to 'warm up' interviewee.

1. What organisation/ project/ service do you work for?

2. What is your job title?
    - Briefly, what does your role involve (what are your key responsibilities)?

## Section B - About the disabled young people involved in decision-making:

We would like to find out more about the disabled young people involved in decision-making.

*For each area of participation work, ask the project worker…*

3. How many disabled children/ young people are involved?
    - What are the ages of the children and young people involved?
    - Is there a range of young people involved e.g. range of disabilities/ range of access needs?

4. How are these disabled young people linked to your organisation/ project/ service?
   Prompts:
    - are the disabled young people your own service users?
    - are the disabled young people a group that work with a range of services?
    - linked to your organisation/ project/ service in some other way?

## Section C - About the participation work:

We are interested in finding out why your organisation/ project/ service involves disabled young people in decision-making in service planning or delivery.

5. From previous conversations we have listed that you involve young disabled people in the following participation work:
    - RESEARCHER TO ADD IN DETAIL

Is that correct?

*For each area of participation work, ask the project worker…*

6. Who started the participation work?
    - When was the participation work set up?
    - Is the participation work a piece of ongoing work or a one-off exercise?

7. Where did the idea for the participation work come from?
   Prompts:
    - disabled young people themselves
    - strategic manager
    - yourself /other project worker
    - other person(s) – who

8. Why was the participation work set up?
    - Have the aims or purpose of the participation work changed over time?

9. What are you hoping to achieve through your participation work?
   Prompts:
    - to steer the overall direction of organisation/ project/ service
    - to deal with operational issues e.g. how services are delivered
    - to make sure the service meets young people's needs and preferences
    - to empower young people
    - to influence decision makers
    - any other aims – if so, tell us more about these

10. Why did you/ your organisation/ project/ service want to involve disabled children and young people in decisions about service planning and/ or delivery?
    - Are non-disabled young people involved in the participation work?
    - **If yes**, why do you involve both non-disabled and disabled young people?

11. Who else is involved in the participation work?
    Prompts
    - other staff

- parents/carers
- support workers
- volunteers
- senior offices
- partner organisations
- staff at a strategic level e.g. board of trustees

## Section D - How disabled children and/ or young people are involved in decision-making:

We are interested in finding out more about what kinds of decisions disabled young people are involved in making.

*For each area of participation work, ask the project worker…*

12. Can you describe which decisions/services the young people are trying to influence or change?

13. Are the young people involved...
    - Making decisions about your own organisation/ project/ service?
    - Making decisions about other organisations/projects/ services?

14. ***If making decisions about your own organisation,*** *can you tell us more about what kind of decisions…*
    - Are these decisions about strategic issues e.g. the development of new services or policies, how the organisation/ project / service is run?
    - Are these decisions about operational issues e.g. what happens day to day?
    - Are the young people involved in decisions about mainstream services (e.g. services for all young people) or specialist services (e.g. for certain groups of young people)?
    - How often do the young people meet?
    - How do they get involved in making these decisions?

15. ***If making decisions about other organisations/project/service,*** *can you tell us more about what kind of decisions…*

- Are these decisions about strategic issues e.g. the development of new services or policies, how the organisation/ project / service is run?
- Are these decisions about operational issues e.g. what happens day to day?
- Are the young people involved in decisions about mainstream services (e.g. services for all young people) or specialist services (e.g. for certain groups of young people)?
- How often do the young people meet?

16. What kind of changes was it hoped that disabled young people's participation in decision-making would bring about?

17. In reality, how much influence do disabled young people have over decisions?

18. What methods have you used to involve disabled young people in decision-making?
    Prompts:
    - creative methods
    - delivering training
    - research/evaluation
    - board or governance structures
    - youth forum/council
    - meetings for all service users
    - advisory groups
    - consultation events
    - any other ways young people participate in decision making

19. Where do you get your ideas for how to involve disabled young people in decision-making?
    Prompts:
    - own experience of supporting participation through their work
    - training

- good practice guidelines (whose guidelines?)
- other staff
- managers
- other sources of information – please tell us more

20. What help/support do disabled young people involved receive to enable them to participate in making decisions?
Prompts:
    - facilitated access (e.g. transport, interpreter, accessible buildings)
    - accessible information
    - training (for their role or on participation/rights)
    - communication support e.g. makaton, IT, talkboards
    - peer mentoring
    - reward and recognition

*If non-disabled young people also involved in participation work, ask the project worker…*

21. How do you ensure that all young people – including disabled young people – have equal opportunities to take part in all activities?

*If not involving disabled young people with more complex needs, ask the project worker…*
Have you experienced any barriers in terms of accessing or working with disabled young people with more complex needs?

**Section E - Impact of disabled young people's participation:**

We would like to find out more about the impact of disabled young people's participation in decision-making.

22. Can you give us some specific examples of things that have been changed and improved as a result of young people's participation?
    - What did it look like before and after?
    - Why is this now improved?
    - How has this had an impact on the service, the wider organisation, the staff, the young people who use the service?

- Has the young people's participation in decision-making led to wider changes in the local area (e.g. other services, in strategies or in policies that affect disabled young people)?
- Has the young people's participation in decision-making led or contributed to wider changes nationally (e.g. national campaigns or policies)?

23. Have young disabled people been involved in finding out what has changed or improved as a result of their involvement in decision-making?
    Prompts:
    - have they helped design evaluations?
    - have they shared their views in evaluation?
    - have they been co-researchers (undertook data collection or analysis)?

24. Through involving disabled young people in decisions, what has changed for other disabled young people who use your own or others services?

25. Do you share information about what has changed or improved as a result of disabled young people's participation?
    - Who do you share this information with?

26. What have you personally learnt as a result of being involved in the participation work?

## Section F - What has worked well and lessons learnt:

We are interested in finding out what has worked in terms of your involvement of disabled young people in decision-making. We want to find out more about what 'good practice' is and what supports it.

*For each area of participation work, ask the project worker…*

27. What has worked well in terms of involving disabled young people in decision-making?
    - Why do you think this has worked well?
    - What helped/supported this (e.g. resources, money, staffing, training)?
    - In your opinion, what does this organisation/ project/ service do really well that has led to high quality participation work?

28. Have you had any difficulties in involving disabled young people in decision-making?
    - How did you overcome these difficulties?
    - Is there anything you would do differently if you had the opportunity?
    - Are there any areas that you are actively trying to improve or learn new practice?

29. What other decisions do you think disabled young people could be involved in the future?

## Section G - Plans for the future

Before we finish the interview, we would like to ask you about the future plans for your participation work.

30. What are the plans for the future of the participation work?
31. Who will decide what happens in the future?
    Prompts:
    - young people currently involved in participation work
    - other young people
    - project worker(s)
    - yourself
    - funder
    - other people – who

32. What would need to happen to further embed participation across your organisation/ project/ service?

33. What advice would you give to similar organisations/ projects/ services about how to involve disabled young people in decision-making?
    - Why should they involve disabled young people?
    - What benefits would it bring to them/their organisation/ project/ service?

34. Anything else you would like to say about the participation of disabled young people in decision-making?

**That's the end of the interview – thank you for talking to us!**

# Disabled young people's topic guide template

**Note for staff researcher:**
Before fieldwork, these questions will need to be modified slightly to reflect the nature of the participation activity (attendance at an adult-led meeting, attending a consultation event, on-going participation projects etc). The questions will also need to be adapted to be used in different ways (interviews, focus groups).

In addition, if young people are involved in a range of participation activities, the topic guide will also need to be modified to capture information about each aspect of this work.

**At the start of the fieldwork, the following will need to be explained:**

- What topics will be covered
- How long it will take
- Ask permission to record or take notes
- Explain confidentiality and anonymity
- Tell them about the research and what we will do with the information they give us – write a report and publish in Sept 2012. All participants will be given a summary of the findings when they are published.
- Explain there are no right or wrong answers. We want to hear their views. Explain they do not have to answer all questions.
- Ask if they have any questions
- Check that they still want to take part.

## A) About you – First we would like to ask a few questions about you.

1)How did you hear about this work?

2)Why did you become involved in this? What motivates you?

## B) Background – We would like to find out a bit more about what you have been involved in.

3) Please can you describe your project/the meetings you attend/the consultation event

4) What are you trying to achieve/do?

5) Which decisions/services are you trying to influence/change? What are you trying to change?

6) Please can you describe what you do/how you are involved?

[Prompts: Which methods do you use to? E.g; made a DVD, sent out a survey, mystery shopping]

7) Please can you describe how the group/meeting/event was/is organised/run?

**C) Satisfaction with participation – We would like to ask you a few questions about whether you feel the participation activity works well.**

8)How many young people take part? (if applicable, how many non-disabled young people take part?)

9)Does everyone get a chance to have a say?

10)What support/help is needed to enable young people to participate?

11)Some young people might need a bit more support/help than others to be involved, do these young people get the help they need?

12)Do/Did all young people in the group/at the event have/had an equal chance to have a say and express their views?
Why do you think that?

13)Are/Were all young people in the group/at the event listened to equally? Why do you think that?

14)Are/were all young people treated the same?

15)Do the young people taking part treat each other with respect?
Please could you explain your answer.

16)Do you get enough help/support to take part in this? If so, what help/support do you get?

17)Do you feel that you can express your views, ideas and opinions (in your group/with strategic managers (the people with the money and power)/with partners? Why?

[Prompts; do you feel comfortable, confident?]

18)Do you feel listened to (in your group/by strategic managers(the people with the money and power/partners)? Why do you feel this? How can you tell?

19) Are there any things that you wouldn't want to talk about?

**D) Impact on young people participating. We would like to ask you a few questions about whether being part of this has made any difference to your life.**

20) How does being involved in this make you feel?
[Prompt: e.g. more confident, good about myself, empowered]

21) Have you learnt any new skills or experienced anything new?

22) Has anything changed for you since becoming involved in this?

23)Has being involved in this work changed your own perception of disabled young people (ie. What you think about them)?

24) Are you given any reward or recognition for being involved? If so, what e.g. Voucher, certificate? How important is this reward/recognition to you?

**E) Impact on services, decisions and other people. We would like to ask you a few questions about whether you feel this work has made a difference to other people.**

25) How do you tell others about the work that you do?
[Prompts: Professionals and other disabled and non-disabled young people]

26) Has sharing what you do had any effect? Eg: have services changed, been asked to do other things, changed peoples perceptions/attitudes

27) What has the project/meetings/events achieved? Please provide examples.

Prompts: Changes in decisions, changes in services, more information, changes in attitudes towards disabled young people, changes in how the strategic managers make decisions *[Researcher to add other prompts according to the information we have gathered on case study]*

28) Has anything changed for other disabled children and young people who use services because of the participation work that has been going on?

If yes, what?

If no, why do you think this is the case?

29) Has this work changed attitudes towards involving disabled children and young people in decisions about services?

If yes, how

If no, what do you think the barriers are/what is stopping this?

30) Have you been disappointed with anything during the work you have been doing?

31) Do you feel satisfied with your role in the decision-making process?

### F) The future

32) What other decisions do you think disabled children and young people could be involved in?

33) Do you know what is going to happen to this work in the future?

34) What would you like to happen?

### Finally,

35) Overall, what do adults need to do to make it possible for more disabled children and young people to be involved in decisions about services?

36) From being involved in participation, what do you think works well?

37) What doesn't work well?

Any other comments

# Appendix C Fieldwork

## Table C.1: Number of interviews, focus groups, and surveys conducted

| Organisation/ service | No. of interviews, focus groups, survey | Total |
|---|---|---|
| A | 1 focus group with young people<br>1 interview with manager<br>1 interview with project worker<br>1 interview with commissioner<br>3 interviews with partner organisations who worked with the group<br>Online survey of special and mainstream schools/colleges linked with the project | 1 focus group<br>5 interviews<br>1 online survey |
| B | 1 focus group with young people<br>1 interview with project worker<br>1 interview with strategic manager | 1 focus group<br>2 interviews |
| C | 1 focus group with young people<br>2 interviews with project workers/managers<br>1 interview with partner who worked with the group | 1 focus group<br>3 interviews |
| D | 1 focus group with young people<br>1 interview with young chair person<br>1 interview with project worker<br>1 interview with commissioner<br>1 interview with partner who worked with the group | 1 focus group<br>4 interviews |
| E | 1 focus group with young people<br>1 interview with manager/project worker | 1 focus group<br>1 interview |
| F | 1 focus group with young people<br>1 short survey of two young people involved in the group (administered by project worker)<br>1 interview with project worker<br>1 interview with strategic manager | 1 Focus group<br>4 interviews<br>1 short survey |

| | | |
|---|---|---|
| | 1 interview with commissioner<br>1 paired interview with two volunteers | |
| G | 1 focus group with young people<br>1 interview with previous young member (now mentor to group)<br>1 interview with project worker<br>1 interview with manager<br>1 interview with practitioner who set up the group<br>1 interview with partner who has worked with the group | 1 focus group<br>5 interviews |
| H | 1 focus group with young people<br>1 interview with a strategic manager<br>1 interview with Chief Executive of voluntary organisation<br>1 interview with Chairperson of voluntary organisation<br>1 interview with development worker of voluntary organisation | 1 focus group<br>4 interviews |

# Appendix D Thematic analysis framework

**A. Description of participation**

- A.1 Background of organisation
- A.2 Background of participation activity
- A.3 Funding
- A.3.1 Reasons for sustainability
- A.4 Interviewee background
- A.5 Objectives & aims of the group, project or activity
- A.6 Policies & strategies for participation
- A.7 Who else involved
    - A.7.1 Other staff
    - A.7.2 Parents & carers
    - A.7.3 Partner organisations
    - A.7.4 Strategic staff
    - A.7.5 Support workers
    - A.7.6 Volunteers
    - A.7.7 Other

**B. Description of young people involved**

- B.1 Characteristics of DYP
    - B.1.1 Age range
    - B.1.2 Impairments
    - B.1.3 Other
- B.2 Support for young people
- B.3 Where and how recruited
- B.4 DYP reasons for joining
- B2.1 Emotional support
- B2.2 Other support
- B2.3 Practical support

**C. Ways DYP currently involved**

- C.1 Description of participation activities &
    - C.1. 1 How DYP involved in the participation
- C.2 Level of decision making
- C.2.1 Adult-led
- C.2.2 Consultation
- C.2.3 DYP-led
- C.3 Operational processes
- C.4 Strategic processes

**D. What works & why**

- D.1 Attitudes
- D.2 Practical
- D.3 Methods
- D.4 Other

**E. Barriers & how**

- E.1 Attitudes
- E.2 Funding
- E.3 Knowledge or understanding
- E.4 Parents
- E.5 Practical
- E.6 Skills

- E.7 Staffing
- E.8 Other & how overcome

**F. Challenges & barriers still facing**

- F.1 Attitudes
- F.2 Funding
- F.3 Knowledge or understanding
- F.4 Parents
- F.5 Practical
- F.6 Skills
- F.7 Staffing
- F.8 Other still facing

**G. Rewards & recognition**

- G.1 Feedback to the DYP group
- G.1.1 Informal & ad hoc dialogue
- G.1.2 Newsletters or visual media
- G.1.3 Reporting back to group, forum or council
- G.1.4 Websites, video, social networks
- G.1.5 Written reports or summaries
- G.1.6 Other
- G.2 Rewards for DYP

**H. Impact and outcomes**

- H.1 Attitudes & relationships
- H.2 Decision-making processes
- H.3 For individual DYP
- H.4 For other DYP
- H.5 For services
- H.6 Funding & sustainability
- H.7 Inclusion
- H.8 National level
- H.9 Other

**I. Evaluation**

- I.1 Evaluation of work undertaken

**J. Dissemination of work**

- J.1 How the group & its work shared

**K. Sustainability**

- K.1 Future work & direction

**L. Advice to others & recommendations**

**M. Any other comments from DYP**

**N. Quotes**

**O. Specific examples of poor practice**